Policy Framework for Services for Children and Youth with Special and Complex Needs and their Families

Alberta Children and Youth Initiative
Partners

Policy Framework

For Services for Children and Youth with Special and Complex Needs and their Families

Ministries of the Alberta Government will work together to plan and implement supports for children and youth with special and complex needs. This Policy Framework demonstrates the commitment to this priority area.

There is no group more important for a healthy Alberta than Alberta's children. Our children and youth are tomorrow's leaders, and the Alberta Government is committed to supporting children in reaching their potential; particularly those who are most vulnerable and may have special needs.

An estimated 10 - 15 % of Alberta's children and youth have special needs. Of the 10 - 15%, approximately 1 % have complex needs and require significant extra-ordinary care due to the severity of their impairment(s).

This policy framework is designed to articulate government's approach regarding provision of services and supports to families with children and youth with special and complex needs. The Framework in particular identifies the increased support needed on a cross-ministry level.

Ministries will work together with regional authorities, boards, contract agencies and community to provide an easily identifiable, integrated response to children and youth with special and complex needs.

The Framework has been developed by a number of Alberta government ministries including:

- Children's Services
- Health and Wellness, including Alberta Mental Health Board
- Learning
- Community Development, Persons with Developmental Disabilities

The partnering ministries of the Alberta Children and Youth Initiative (ACYI) identified that families are facing an increasingly complex service system and often experience jurisdictional barriers when seeking services for their children.

Parents have also identified significant concerns with gaps in services. Families with children and youth with complex needs, in particular, have expressed the need for an easily identifiable integrated response across government ministries, service providers and communities.

The integrated, cross-ministry system of supports and services defined in this framework will support families by meeting their needs for information and access to services for their children and youth with special and complex needs.

> ***An integrated, cross-ministry system of supports and services can assist in optimizing the well-being of children and youth with special and complex needs***

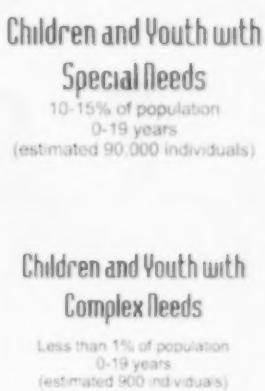
The policy directions identified in this framework are expected to promote the following important outcomes:

- Collaborative regional planning
- Appropriate and effective sharing of information for integrated planning
- Coordinated long-term service plans
- Integrated, coordinated and consistent service delivery
- Families who are well-informed and involved
- Families who are satisfied with access to required services and supports, the way services are provided, and the quality of services they receive

Children and Youth with Special and Complex Needs

For the purpose of this policy framework, children and youth with "**special needs**" are those children and youth with impairments that limit their ability to participate in their daily activities at home, in school, and in their communities. Their impairments can be in one or more of the following areas:

- Cognition
- Communication
- Sensory/motor
- Social/emotional/behavioural
- Self-help (adaptive)
- Exceptional health needs



Children and youth with "**complex needs**" differ from those with special needs in that they require significant extraordinary care due to the severity of their impairment(s) and require services from more than one ministry. Those who require such services may include children and youth:

- With multiple impairments, complex mental health and health issues and/or severe behavioural needs
- For whom all currently available resources have been utilized with limited success
- Who require fiscal and human resources that strain the capacity of any one ministry
- For whom there are questions about the safety of the child, youth, family, or public

Some Sample Case Studies

Carol:

Carol is a 17 year old with a degenerative brain condition. She is developmentally delayed and has an IQ of 40. She is impulsive and her behaviour can be violent and out of control. She has had numerous medical and other assessments and has been hospitalized many times. Carol lived with her parents until age 14 when they could no longer manage the level of care she needed at home. She now resides in a residential facility with up to three staff caring for her at all times. Carol has complex needs and her family expresses frustration in trying to get services from three ministries - Children's Services for 24-hour residential care; Health and Wellness for hospital placements, professional services of neurologists and psychiatrists, and medications; Learning for the provision of special education services.

Bradley:

Bradley is a 2-½ year old with Down's Syndrome, with a heart defect and other Down's Syndrome related health conditions, as well as respiratory problems. His functioning is delayed and he requires total care and constant supervision, including tube feedings and oxygen during periods of illness. Bradley primarily lives with his aunt and uncle but also at the home of his father and paternal grandparents who provide respite care. Bradley's care requires the involvement of many ministries to effectively coordinate and plan the necessary services and supports.

Lisa:

Lisa is a 17 year old with progressive damage of the bone marrow and areas of her brain, with secondary conditions including diabetes, asthma, and extreme behavioural problems. She has been assessed as functioning at a 9 -12 year old level. She is confined to a wheelchair. Lisa lived at home with her parents until she was 16, when she was placed in a continuing care facility as she requires 24-hour supervision. Lisa's care requirements are beyond the capacity of a single ministry to manage.

Policy Framework Vision

The vision and following guiding principles provide direction for integrating supports, services, and future policy development.

Families with children and youth with special and complex needs receive the coordinated supports necessary to achieve optimal development and well-being of their children at home and in their communities.

This vision complements the Alberta Government's goal that children and youth will be supported in reaching their potential.

Guiding Principles

- **Family centered** - families have the primary responsibility and capacity to care for their children and will be actively involved in planning for services
- **Shared responsibility** - families, professionals, communities and governments all contribute to development and coordination of services
- **Coordinated and integrated access** - families with children and youth with special and complex needs will have access to coordinated and integrated services
- **Children and youth focused** - services and supports respond to changes from infancy through to adulthood
- **Individualized supports** - flexible, available and affordable services based on individual needs
- **Comprehensive -** access to a continuum of supports and services that are flexible, accessible and comprehensive
- **Culturally sensitive** - values, traditions, languages and cultures of all people are acknowledged, recognized and respected
- **Aboriginal Culture -** the culture and traditions of Aboriginal children and youth are acknowledged, recognized and respected
- **Accountability** - families can access the most effective services and reports
- **Evidence-based interventions** - new research regarding evidence-based interventions and therapies will be reviewed and appropriately applied

Policy Directions

Policy Direction #1: Management of Integrated Service Delivery for Children and Youth with Complex Needs and their Families

The service needs of some children and youth are complex and cannot be easily addressed or delivered by a single human service organization in isolation of other service providers. Dealing with the overlapping issues concerning children and youth with complex needs requires a holistic and multi-disciplinary approach.

Formalization of an integrated case management model will be implemented for children and youth with complex needs so that various ministry partners, regional authorities, and service providers involved in the child's life work together to address the child's and family's needs.

Included within this model are regional integrated case management teams that will formalize the processes of early identification, assessment, planning, and service delivery, monitoring and evaluation. The model also includes provincial supports to assist regions in providing coordinated services, including access to a provincial cross-ministry team that will provide timely clarification and resolution of policy and mandate-related issues.

Policy Direction #2:

Cross-ministry Collaboration for Children and Youth with Special Needs and their Families

While established processes are required for children and youth with complex needs, there is also a need for ministries and regional authorities to work more collaboratively on behalf of all children and youth with special needs. Even though their needs may not be complex, children with special needs often access supports from more than one ministry.

Ministry partners, regional authorities, and service providers will be proactive and collaborate in resolving issues for families with special needs when the issue affects more than one ministry.

This policy direction clearly identifies the expectation that when services and supports are being provided from more than one ministry, and issues arise related to meeting the child's or youth's needs, ministry partners, regional authorities, and service providers will work together to resolve the situation for the family.

Policy Direction #3: Sustainability of Services/Transition Planning

Integrated cross-ministry planning is required to sustain services for children and youth with special and complex needs as they move through the various transitional phases of their life, such as pre-school to school age, and adolescence to adulthood.

Formal transitional planning for children and youth with special and complex needs will be guided by transitional planning protocols, including transitional planning beginning 24 months prior to a youth turning 18 years and resulting in the development of a transitional plan 12 months before the youth turns 18 years. The transitional plan will address issues such as placement, educational, social and other pertinent needs.

Policy Direction #4: Cross-ministry Information Sharing

Collaborative and integrated service delivery is based on the ability to share needed health information within the provisions of privacy legislation; on the capacity of service providers establishing and maintaining a knowledge base of available resources; and ministry partners, regional authorities, and service providers having common information systems regarding the types of services and supports needed by children and youth.

Cross-ministry information sharing initiatives will be implemented, including development of information sharing guidelines and training tools for delivery staff; regularly updated resource information for families; and steps to improve ministry and regional information systems to identify common language, definitions, diagnostic and prognostic coding.